

# LeDeR Newsletter

A newsletter brought to you by CWICB – October 2022

**Welcome** to our third issue of the Coventry & Warwickshire Integrated Care Board LeDeR newsletter.

## What is the LeDeR programme?

### ***Learning from lives and deaths – people with a learning disability and autistic people (LeDeR).***

LeDeR is a service improvement programme for people with a learning disability and autistic people.

Established in 2017 and funded by NHS England and NHS Improvement, LeDeR works to:

- *improve care for people with a learning disability and autistic people*
- *reduce health inequalities for people with a learning disability and autistic people*
- *prevent people with a learning disability and autistic people from early deaths*

## LeDeR Reviews:

A LeDeR review looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes. We look for areas that need improvement and areas of good practice. This helps reduce inequalities in care for people with a learning disability and autistic people. It reduces the number of people dying sooner than they should.

Anybody can make a referral to LeDeR, if they believe that a person that has died had a learning disability (and was aged 4+) or was autistic (and was aged 18+).

This can be done via the following link:  
<https://leder.nhs.uk/report>

## LeDeR Governance:

We have a dedicated LeDeR Governance Group which takes place on a monthly basis. Senior health and social care representatives from across Coventry and Warwickshire attend the meeting, consider findings of reviews, and oversee an action plan linked to the learning.

## LeDeR Annual Reports:

The 2021/22 LeDeR Annual Reports were published earlier this year and they are attached:

1. [Coventry & Warwickshire LeDeR Report 21/22](#) 
2. [National LeDeR Report 21/22](#) 
3. [LeDeR 'Take Home' Fact Sheet](#) 

Since 1<sup>st</sup> April 2022, Coventry & Warwickshire LeDeR Programme has had:

### **26 Notifications.**

26 reviews have been completed (15 Initial and 11 Focused) and 3 were out of scope.

There are currently 24 reviews on the system, with 7 on hold whilst we await the outcome of other investigations.

### Key learning taken from reviews:

- Poor communication between the person, relatives and services
- Lack of face to face reviews, e.g. GP appointments and social care reviews
- Both *learning disability* and *Down's syndrome* being listed on the cause of death certificate
  - Lack of mental capacity assessments taking place.

### Examples of Positive Practice (taken from reviews):

#### Primary Care:

- ✓ Very thorough and effective Learning Disability Annual Health Checks carried out by the GP practice

#### Coventry & Warwickshire Partnership NHS Trust:

- ✓ The person was very well supported by the Community Learning Disability Team

#### Acute Trusts:

- ✓ A Hospital Passport was completed prior to admission and good use of the Acute Liaison Team was made during admission

#### Multiple organisations working well together:

- ✓ An early referral was made to the Palliative Care Team. Joint end of life discussions took place across the Multi-Disciplinary Team, also involving the patient. The appointment of an Independent Advocate was made at the earliest possible opportunity.

### Other News & Information:

#### Support for Carers:

It is vitally important to consider the wellbeing of people who care for someone with a learning disability, an autistic person or indeed any form of disability, as being a carer for someone can sometimes take its toll on a person's emotional, mental and physical health.

The **Carers Trust Heart of England** covers the Coventry & Warwickshire area and it is there to help adult and young carers by providing wellbeing support, assessments, peer to peer support, up-to-date guidance and information, and activities or breaks, amongst many other services.

The link to their website is: [Carers Trust Heart of England](#)

#### A Guide to the Mental Capacity Act:

We have recently produced an easy-read document which explains the Mental Capacity Act, which was done in collaboration with people with lived experience from Grapevine.

Please feel free to share this via the following link, with any organisations, teams and people with a learning disability that you feel would benefit from having this resource: [A Guide to the Mental Capacity Act \(easy-read\)](#) is attached 

#### Reasonable Adjustments (SMALL CHANGES = BIG DIFFERENCE!):

Please take some time to watch the following two short videos regarding the importance of making Reasonable Adjustments for people with a learning disability and/or autistic people, and the vital role these play in reducing health inequalities:

[Video #1](#) (featuring a carer/parent and professionals)

[Video #2](#) (featuring people with lived experience)

In each edition of this newsletter, we will share information based upon a key theme of our LeDeR learning.

Spotlight on:  
**Bowel Health Awareness**

***Whilst one LeDeR review in 2022/23 listed Constipation as an actual cause of death, there are a large number of LeDeR reviews that show Constipation as being an active problem for people during their lives.***

**Some facts**

- Bacteria and waste in a person's stool can pose risks to health
- Changes in the colour, shape and texture of stool can reveal signs of infection, digestive issues or serious health problems, such as cancer
- Constipation & Impaction can be very serious and life threatening

**Signs & Symptoms of poor Bowel Health**

- Disproportionate feeling of fullness
- Consistency or colour of stool (Diarrhoea/Hardfaeces)
- Cramping and pain (incl. back pain)
- Bad breath
- Change in behaviour/agitation
- Sleep disturbance
- Bleeding from bottom and/or blood in stool
- Lump in stomach
- Indigestion or severe gas
- Difficulty in sitting comfortably
- Changes in toileting frequency
- Lack of appetite
- Haemorrhoids
- Vomiting
- Headaches
- Urine retention
- Unexplained weight loss
- Extreme tiredness
- Distended or swollen abdomen, bloating
- Increased seizure activity

**Supporting good Bowel Health**

- Nutrition which contains sufficient fibre, water and healthy foods
- Wholegrain cereals
- Fluid intake (1.5 to 2 litres per day)
- 5 portions of fruit and vegetables daily: apples, peas, broccoli, apricots, grapes (and raisins), peaches, pears, plums (and prunes), raspberries and strawberries
- Exercise
- Regular medication reviews


**Useful online links:**

[Dimensions brief guide to constipation](#) - (short video)

[Risks & causes of Bowel Cancer](#) (Cancer Research UK webpage)

[Symptoms of Bowel Cancer](#) (Bowel Cancer UK webpage)

[How to do the FIT Bowel Cancer screening test](#) (short video)

The **Bristol Stool Chart** is widely used as a research tool to evaluate the effectiveness of treatments for various diseases of the bowel. The chart is used to describe the shapes and types of stools. It is also used as a tool to diagnose constipation, diarrhoea and irritable bowel syndrome. The chart can [Bristol Stool Chart](#) is attached 

### **Upcoming Learning Opportunities:**

In collaboration with the Warwickshire Learning and Development Partnership, we have commissioned a range of training sessions linked to themes that arise from LeDeR learning. These sessions are open to anyone who cares for or supports a person with a learning disability and/or autism.

If you are interested in attending any of these sessions (listed below), please email:  
**warwickshirelearninganddevelopmentpartnership@warwickshire.gov.uk**

Course: **Dysphagia**  
Date: 27<sup>th</sup> October 2022  
Time: 10:00 – 12:00  
Venue: Webinar (Microsoft Teams)

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Course: **Diabetes**  
Date: 3<sup>rd</sup> November 2022  
Time: 09:30 – 11:30  
Venue: Webinar (Microsoft Teams)

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Course: **Bowel Health Management**  
Date: 22<sup>nd</sup> November 2022  
Time: 13:00 – 14:30  
Venue: Webinar (Microsoft Teams)

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Course: **Diabetes**  
Date: 7<sup>th</sup> December 2022  
Time: 09:30 – 11:30  
Venue: Webinar (Microsoft Teams)

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Course: **Dysphagia**  
Date: 8<sup>th</sup> December 2022  
Time: 10:00 – 12:00  
Venue: Webinar (Microsoft Teams)

### **USEFUL ONLINE LINKS**

[LeDeR - Home](#)

(For more information about the national LeDeR programme)

[Coventry & Warwickshire Partnership NHS Trust - Learning Disability Services](#)

(Overview of services, contact details and LD Annual Health Check resources)

[What are Reasonable Adjustments and why are they important?](#)

### **KEY CONTACTS**

***For further information about our local LeDeR programme, please feel free to contact:***

Jenny Burgin – Senior LeDeR Reviewer: [jennifer.burgin1@nhs.net](mailto:jennifer.burgin1@nhs.net)

Karen Morris – LeDeR Support: [karenmorris3@nhs.net](mailto:karenmorris3@nhs.net)

**Feedback on the usefulness of this newsletter would be welcomed and appreciated, such as whether you find the content useful, whether you feel that anything in particular is missing, or whether you feel that less or more detail is needed. Please email any feedback to [dougie.philippou@nhs.net](mailto:dougie.philippou@nhs.net)**